# Narfan Association UK

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# **Publications 2008**

Reg Charity No: 802727 (Estab 1984) Web: www.marfan-association.org.uk Email: marfan@tinyonline.co.uk

1. Marfan Emergency Card

**- £2** *Free to members* }

Annual Subscription is £15 per year

1a. Marfan "In Touch" Magazine - £3 Free to members }

due 1<sup>st</sup> Feb. annually (£22 overseas)

#### Basic Pack - £10 (incl postage & packing)

- 2. Fact Sheet on Marfan Syndrome 2006
- 3. A4 Large Marfan Fact Book on MFS 2002
- 4. Pamphlet for the Ophthalmic Profession 1997
- 5. Pamphlet for the Chiropody Profession 2003
- 6. Pamphlet for the Dental Profession 2002
- 6a.Pamphlet Musculoskeletal Problems 2002
- 6b.Pamphlet-Psychosocial Aspects 2002
- 6c.Pamphlet for ENT Surgeons 2002
- A4 Clinical Guide is included for doctors 2002

Research Results – European Marfan Study 2005

### Further Reading - £3 each item

- 7. Emergency Diag & Treat of Aortic Dissection 1998
- 8. Booklet Before & After Birth 1998
- 9. Booklet for Teenagers 2005
- 10. Booklet-A Very Special Mouse -for children 1990
- 11. Booklet for Teachers 1993
- 12. Booklet Fun with Fundraising
- 12a Booklet Gospel Poems Relaxation with Jesus
- 12b Booklet Gospel Poems A Moment with Jesus Set of Pamphlets - £1.00

"Support for Today with Tomorrow in Mind"

#### 13. MARFAN VIDEO 2000 - £15 per copy – 2hrs. 35 mins.

Scoliosis Management; Eye Problems; Aortic Surgery; Research Update; the Teen'Years; the Marfan Association UK 13a. MARFAN VIDEO 2003 - £15 per copy - 2hrs. 47 mins.

International Research Update; Ear, Nose and Throat; Orthotics; European Marfan Study Findings 13b. MARFAN INFO TAPE FOR THE VISUALLY IMPAIRED - £4 donation 13c. WAYNE'S RECIPE BOOK - "A Zest for Life" - £4 per copy

## Information Leaflets - Min. of 50p per item helps us to re-print - Thank you

- 14. Care of Symptomatic Marfan Joints 2002
- 15. Role of Nutrition in Irritable Bowel Synd 2001
- 16. Pain Management 2001
- 17. International Research Update 2002
- 18. Genetic Testing in Marfan Syndrome 2002
- 19. The Use of Hormone Treatment 1997
- 20. Dental Health for Heart Patients (B.H.F)
- 21. Living With Marfan Syndrome 2004
- 22. Pregnancy in Marfan Patients 1996
- 23. Genetics & Insurance Brief Survey Result 1997
- 24. Addressing Special Needs of Siblings 1997
- 25. Simon's Poem teens view, living with MFS 1985
- 26. Advice for the Older Marfan Patient
- 27. Revised Diagnostic Criteria (Ghent) 1996
- 28. Marfan syndrome and the Eye 2004
- 29. Research Developments 2005
- 30. Advice Regarding Feet & Footwear 1996
- 31. Physiotherapy for Joint Hypermobility 2004
- 32. Article: Midwives' Journal & Reply-1996
- 33. Sports Guidelines 1993
- 34. FBN1 Mutation Screening 2005
- 35. Incidence of Osteopenia in MFS 1995
- 36. Joint & Skin Manifestations Prevalent- 1995
- 37. MFS & Overlapping Conditions 2002

- 38. Impact on the Whole Family 2004
- 39. Management of Eye Problems 2004
- 40. Inherited Ophthalmic Disorders 2006
- 41. Orthopaedic Aspects of MFS 2005
- 42. The Alexander Technique 2004
- 43. Fact Sheet Large Print
- 44. Infantile & Neonatal Marfan Syndrome 1995
- 45. Marfan Research Update 2004
- 46. Obstructive Sleep Hypopnea 1995
- 47. New Hope for Marfan Lit Review 2006
- 48. Health Supervision Birth to 21 yrs 1999
- 49. Genetics and Insurance 2001
- 50. Practical Paediatrics in MFS 2002
- 51. General Medical Research Report 2002
- 52. ENT, Bone & Joint, & Dental Aspects 2002
- 53. Info Day Workshop Growing Older 2002
- 54. Info Day Workshop- Marfan and the Mind 2002
- 55. Info Day Workshop Growing with MFS 2002
- 56. Joint Hypermobility patient survey 2003
- 57. Marfan and Pilates 2003
- 58. Orthotic Management of the Ankle/Foot 2003
- 59. Losartan "A Whole Lot of Optimism" 2005
- 60. Ageing and Marfan Syndrome 2002
- 61. Joint Hypermobility Syndrome (pain mgmt) 2003